

Last revised February, 2022

Aware in Care®

Better Lives. Together.



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Ambassador, Aware in Care, Parkinson's Foundation President, BOD, Parkinson's Assoc of San Diego Ambassador, Davis Phinney Foundation Advocacy Ambassador, Michael J Fox Foundation

Better Lives. Together.



Potential Issues during Hospitalizations/ER Visits

How to prepare

Better Lives. Together.

Why Are We Here Today?



To help people affected by Parkinson's:

- Understand the risks associated with hospital stays.
- Get tools to play an active role in their care.
- Be prepared for a hospital visit, whether planned or unplanned.
- Develop strategies to get the best possible care in the hospital.

To be Aware in Care®

Physicians



Emergency Room Physicians - experts in high volume cases - i.e. sepsis, stroke, heart attack

Hospitalists - will be assigned to manage your care

Your neuro or MDS - won't know you're there

Intensivists - will manage your care in Intensive Care

Expert on YOUR PD - you and your care partner

Nursing



Rigid rules related to timing of med dosing result in medication errors

Activity orders

Workload - as many as 5-7 patients/nurse

BE VOCAL. BE PERSISTENT!!

Pharmacy and Hospital Procedures



Medication substitution

Timing of medication administration

Method of dosing: Parcopa, Duopa, Usual medications

Utilization of patient's own medications

Hospitals Are Safe, Right?



"They will call my neurologist."

"The pharmacy will have my PD meds."

"Staff will understand PD symptoms"

"They will bring me my meds on time."

"They will know the drugs that are unsafe."

Inpatient care of people with Parkinson's



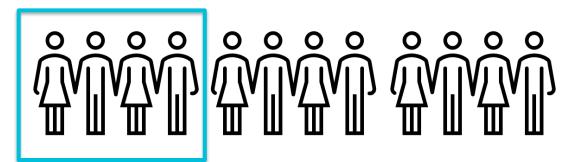
Compared to control cohorts, PD patients have:

- Higher rate of hospitalization
 - 44% more often than their peers without Parkinson's.¹
- Longer duration of hospitalization
 - by 2-14 days (varies across studies) ^{1,3}
- Avoidable complications are higher than for their peers without Parkinson's^{1,2,3}
- Less likely to be sent home after hospitalization
 - On average 62.9% discharged to a facility (Assisted Living, Nursing Care, or Rehabilitation)
 - Only 33.2% discharged to their home
 - 3.9% resulted in inpatient mortality⁴
 - 1. Aminoff MJ., et al. Parkinsonism and Related Disorders, 2010.
 - 2. Derry CP, et al. Postgrad Med J., 2010. 86 (1016): 334-7
 - 3. Guttman M, et al. Movement Disorders, 2004 19(1):49-53.
 - 4. Mahajan 2016 J Clin Neurosci

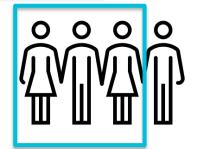
Imagine 12 people with Parkinson's



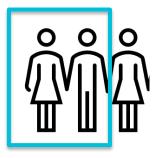
4 of them will be hospitalized this year.



Of those 4, 3 won't get the right medicine on time



Of those 3, 2 will have complications as a result



2 of every 12 people with Parkinson's (or 1 in every 6) will have avoidable complications because the hospital doesn't understand their needs

MJ Aminoff, et al. Parkinsonism and Rel. Disord. 2011. 17:139-145. KN Magdalinou, et al. Parkinsonism and Rel. Disord. 2007 Dec;13(8):539-40. OHH Gerlach, et al. BMC Neurol. 2012.

Medication Changes - MODS



Missed:

• Medications are missed entirely by error, often because PD is not mentioned or listed in the electronic medical record (EMR) if the presenting issue is not explicitly and directly related to PD.

Omitted:

- Medication is withheld intentionally when a clinician incorrectly assumes that
 - NPO indicates that PD medications should also be omitted
 - Severe difficulty swallowing (dysphagia) justifies the omission of medication.

Delayed:

 Medications are not distributed precisely at the home schedule, but rather follow the standard onehour window and/or were set to the hospital standard distribution schedule.

Substituted:

- Distribution of medication other than the exact medication taken by the patient because it is not available on formulary. Improper substitutions include exchanging:
 - Immediate release and continuous
- Generic and name brand.

Medications



Anti-Parkinson medications are as necessary to a Parkinson's patient as insulin is to a diabetic.

"Often, PD medication schedules are changed in the hospital...This change may result in greater risk for disability and consequently an increased risk of accidents and other complications. The acute discontinuation of PD medications...can be life-threatening."

MJ Aminoff*, et al., Management of the hospitalized patient with Parkinson's disease: Current state of the field and need for guidelines. *Parkinsonism and Related Disorders*. 2011

Why is this Happening?



- Lack of Awareness of the critical importance of Parkinson's medication timing.
- Lack of Awareness that poorly managed
 Parkinson's might result in mental confusion and other serious symptoms.
- Lack of Awareness that many common medications for pain, nausea, depression and psychosis are unsafe for people with Parkinson's.

Even in the **BEST HOSPITALS**Even when treated by **CENTERS OF EXCELLENCE UNLESS** we intervene

What To Do???



- Insist upon right med, right time, every time for dosing of medications
- If NPO, consider Parcopa for levodopa
- For Surgery
- Express concerns during pre-op visit
- Talk to anesthesiologist
- Consider conscious sedation, local or regional anesthesia
- Continue meds until just before surgery
- Restart meds asap
- Have another person advocate for you

Medications of Concern



- AVOID

CAN BE USED

Abilify

- Thorazine

- Haldol

Risperdal

Seroquel

Clozaril

Nuplzid

Reglan

- Compazine

- Phenergan

Zofran

Anzemet

Granisol

Always Remember -



Each person with PD has a unique combination of medications and listed regimen.

Each person with PD has the best knowledge of their disease and other conditions but may have communications challenges.

Care partners can have all of the above information and advocate for the person with PD.

The Aware in Care Materials should be used from Admission through Discharge to ensure best practices are followed

Aware in Care Is Here to Help



	•		
Care partner and family Hospital/facility staff	Care partner and family Hospital/facility staff	Person with Parkinson's	Healthcare providers
		Care partner and family	Hospital/facility staff

Stories from the Helpline



"The doctor was about to give me Haldol... I said I looked it up in my kit and it's not appropriate for people with PD..."

"This was my first time at a hospital when a nurse was aware of the importance of meds being on time for Parkinson's patients."



Aware in Care





Materials designed to help people with PD and Care Partners educate and advocate for better care in the hospital

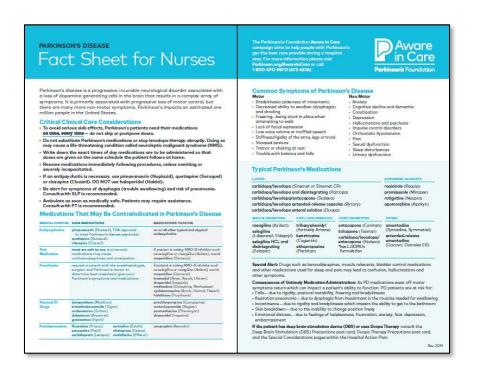
- Online Download (Free)
- Aware in Care Packet (Free)
- Aware in Care Kit (\$8 Shipping charge)

To Download or Order Kit Materials, visit:

Parkinson.org/AwareinCare

Key Materials for People with PD





Fact Sheet for Nurses (Tear-Off Pad):

Share vital information about Parkinson's with every member of your care team

- Critical Care Considerations
- Medications to Avoid and Safe Alternatives
- Common PD Symptoms
- Typical PD Medications
- Info about DBS and Duopa

Key Materials for People with PD





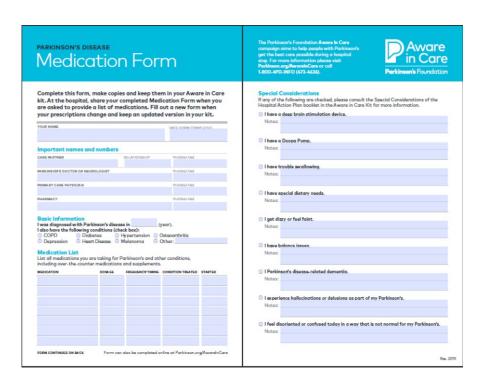
Medical Alert Card

Fill in your card with emergency contact information and place in your wallet.

- Personal Information
- Medications to Avoid and Safe Alternatives
- Important Medical Information for Healthcare Providers
- "I AM NOT INTOXICATED."
 Please call my family or physician for help."

Key Materials for People with PD





Medication Form

Complete this form and keep copies in your kit for use at the hospital. If you download the form, you can fill it out on your computer before you print it out.

- Personal Information
- List YOUR medications with dosage, frequency/timing, etc.
- Check off YOUR Special Considerations (DBS, Duopa, Dementia, Confusion, etc.)

Additional Materials for People with PD





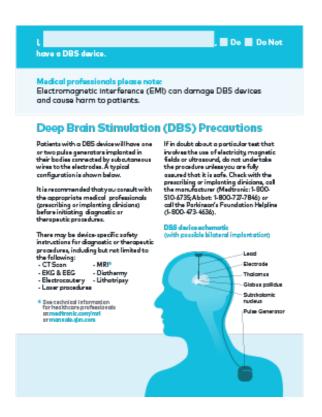
Hospital Action Plan

Read about how to prepare for your next hospital visit — whether it is planned or an emergency.

- Six Steps to Optimum Care
- Checklist For A Planned Hospital Stay
- Checklist For An Emergency Situation
- Special Considerations

Additional Materials for People with PD





Deep Brain Stimulation Info Card

If you have had a deep brain stimulator implanted, share this information with anyone providing medical care to you in the hospital.

- DBS Precautions
- What You Need to Know About DBS
- Checklist For An Emergency Situation
- Device-specific safety instructions for diagnostic or therapeutic procedures

Precautions for DBS



Most HCP's have no knowledge of DBS

Will interfere with EKG/EEG

Are surgeon & anesthesiologist aware

May need to turn off - with electocautery

MRI only with preauthorization and with appropriate precautions

Caution with CT scan
NO Diathermy
Reminders to turn
back on

Additional Materials for People with PD





Duopa Info Card

If you use the Duopa pump, share this information with anyone providing medical care to you in the hospital.

- Three Components to Duopa Therapy
- What You Need to Know about Duopa Therapy
- Duopa Therapy Precautions

Precautions with Duopa



Many HCP's do not know about Duopa/pumps

Contact MDS or rep if pump not utilized

Pump is not water proof

NEVER stop infusion from pump abruptly

Precautions with ultrasound, MRI, EKG, and xray

Assure that your surgeon and anesthesiologist are aware

Physical Therapy and Speech Therapy



Ask for PT eval and treat

Get up and move!

Risk for loss of lean body mass

Risk for debilitation

Risk for dysphagia

Speech therapy consult

Evaluate for swallow function, cognition, speech

Risk for aspiration pneumonia

Nutrition and Neurology



Ask for a nutrition consult with Registered Dietitian

If timing of meals and medication dosing are problematic

If NPO (no food by mouth)

If enteral (tube) feedings are required

If you are not tolerating food/liquids

Your Movement Disorder Specialist likely will not see patient in hospital

Ask that your movement disorder specialist/neurologist be notified of admission

Ask for Neurology hospitalist consult

Aware in Care Summary



Aware in Care® is a national campaign to:

Prepare and empower people with Parkinson's disease, through tools and information, to be your own advocate in the hospital setting, and an engaged partner in your healthcare overall.

Educate healthcare providers and staff to help people with Parkinson's get the best possible care while in the hospital (or other in-patient setting – rehab, LTC, etc.).



Aware in Care Ambassadors



Parkinson's Foundation Volunteers trained to:

Educate the Community

If people with Parkinson's know what they need, they are more likely to get appropriate care.

Educate Clinicians who treat Parkinson's

If clinicians help spread the word about resources, we can share them with more people with Parkinson's.

Educate Hospital Staff

If staff know what people with Parkinson's need and why, they are more likely to adjust the care given.

Aware in Care Is Made Possible by...







...And individuals like you. Thank you for your support.

The Parkinson's Foundation



The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. In everything we do, we build on the energy, experience, and passion of our global Parkinson's community.

Learn more online at Parkinson.org or call the Parkinson's Foundation Helpline at 1-800-4PD-INFO.